



Research Priorities for Service User and Carer-Centred Mental Health Services

Summary of findings from a national consultation

This brief report presents the findings from a consultation exercise to identify priorities for mental health research in England. The consultation was conducted by the Sainsbury Centre for Mental Health, and aimed to give everyone with an interest in mental health services, including service users and their families and carers, an opportunity to influence the national research agenda.

The consultation was commissioned by a Governmental body, the NCCSDO*, as part of their service user and carer-centred services research programme.

'Service user and carer-centred services' are ones which prioritise the needs and aspirations of individual service users and carers, and which involve them both in their own care, and at the organisational level.

How the consultation was conducted

Over a thousand people contributed to the consultation via a series of questionnaires, focus groups and one-to-one interviews. These people included:

- *'Service users'* – people with personal experience of accessing mental health services provided by a variety of sources, e.g. by GPs, specialist NHS services and the voluntary sector
- *'Carers'* – people with experience of caring for a family member or other person who has used mental health services
- *'Professionals'* – people who work in mental health or related sectors, including practitioners, academics, health service management etc.

Many of the participants fell into more than one of these categories. Approximately one half declared having some personal experience of service use and/or caring roles.

The research priority areas described in this report were identified by thematic analysis of the contributions made by these people. Participants were also invited to rate the areas identified, in terms of importance.

* National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development

Findings: Research priorities

The consultation identified 12 research areas which should be prioritised if mental health services are to become more centred on the needs and aspirations of the people who use them, and their families and carers. These are summarised below. More detailed descriptions will be published later in the year.

Key priorities

The strongest consensus exists behind the following four research areas. These areas were rated highly by all groups of participants – service users, carers and professionals.

- **GPs and primary care**
Research is needed to improve the support provided within primary care for people with mental health problems. Particular issues of concern include the early detection of mental health problems within primary care, support for 'common mental health problems', and provision of physical healthcare for people with mental health problems
- **Prevention and promotion**
Research is needed to develop interventions which prevent people from becoming mentally unwell, and interventions which promote mental well-being in the general population
- **Non-medication based interventions**
Research is needed to improve access to effective interventions other than medication – particularly psychological therapies, self-management techniques and approaches based on diet and exercise
- **Social inclusion and the role of mental health and social care services**
Research is needed to explore how various services (e.g. day centres, housing services, employment services) can help people who use mental health services to become more involved in wider society

Priorities for service users

For people who use mental health services, the top priority is for research aiming to improve services for people in crisis:

- **Services for people in crisis**
Research is needed to improve the quality of services for people in crisis, including acute inpatient wards and alternatives such as crisis houses and home treatment teams

Service users also prioritised research which would enable people to take more control over planning their own care and recovery:

- **Person-centred care planning**
Research is needed to enable services to adopt a flexible, collaborative approach in which people are involved in planning their own care, e.g. using the Care Programme Approach (CPA), Wellness and Recovery Action Plans (WRAP), advance directives etc.

Priorities for carers

Carers' highest priority was for research examining their own role in the mental health system:

- **Supporting and empowering family members and carers**
Research is needed to enable services to give better support, information and advice to family members and carers

Priorities for marginalised groups

Service users and carers from various marginalised groups drew attention to the need for research examining the treatment of mental health issues within the criminal justice system. These marginalised groups included people from black and minority ethnic groups, people who have had experience of living without a stable home, and people who have been in prison.

- **Mental health within the criminal justice system**
Research is needed to improve the quality of mental health care available within the criminal justice system and other secure settings, and the ability of Police and other staff to deal competently with mental health issues

Our full report to the NCCSDO also discusses research issues relating to other marginalised groups, including: children; older people; women; people with learning difficulties or autistic spectrum disorders; deaf people; and lesbian, gay, bisexual and transgender people.

Other priorities

The consultation identified four further areas. These were not amongst the highest rated areas, but we would like to stress that the overwhelming feedback from participants was that all 12 research areas should be considered as priorities.

- **User and carer involvement in service planning and delivery**
Research is needed to enable meaningful and representative involvement of service users and carers in planning and delivering services, including through user-led services
- **Medication and side effects**
Research is needed to ensure that medication is used in the most effective and acceptable way, with particular regard to minimising side effects and maximising user choice and control. This is an area of concern particularly for older service users and children.

- **Workforce issues**
Research is needed to clarify the workforce, skill mix and team working arrangements required to allow services to become more user & carer-centred e.g. in acute inpatient wards, crisis resolution teams and community mental health teams
- **Care pathways and transitions between services**
Research is needed to improve the acceptability and efficiency with which service users move between different parts of the mental health system, for example from GPs to specialist services, from child and adolescent to adult services, or from adult to older adult services

Cross-cutting issues

The consultation also highlighted three crucial cross-cutting issues relating to the way in which research is conducted and put into practice. These three issues must also receive attention, in order for research to deliver the improvements sought by service users, carers and professionals.

- **Putting research into practice and disseminating findings**
Mechanisms for putting research into practice and disseminating findings (including to service users and carers) need to be improved. Participants in the consultation observed that the failure to implement research findings “devalues research”. Suggestions were made as to how a more efficient system for implementing research findings might be constructed.
- **Wider use of qualitative research methodologies**
Several of the areas identified by the consultation may be more amenable to qualitative research than quantitative techniques such as Randomised Controlled Trials. In order to meet this need for high quality qualitative studies, appropriate methodologies will have to be developed, researchers will need to be adequately trained in these methodologies, and the outputs from such studies will need to become better accepted by academics and policy makers.
- **Service user and carer-centred outcome measures**
Improved outcome measures will be needed both for research purposes (e.g. in evaluation of effectiveness studies) and for delivery of service user and carer-centred services. These outcome measures would emphasise attainment of life goals of importance to the individual service user, rather than reduction in symptoms.

What happens next?

We contend that organisations involved in the funding of mental health research should consider these findings when deciding what research to fund in future. A full report will be sent to key organisations once it has been peer reviewed by the body responsible for commissioning this project, the NCCSDO. To receive further details about this report, when available, please email:
ResearchPriorities@gmail.com